

**A review of processes and outcomes in family-centered services for children with a disability**

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Running Head: FAMILY-CENTERED SERVICES

A Review of Processes and Outcomes in Family-Centered Services  
for Children with a Disability

### Abstract

The importance of being ‘family-centered’ when providing services to children with a disability and their families has gained currency in the research and practice literature. A growing body of evidence has validated many of the theoretical links between the help-giving practices of staff and desirable outcomes for families with a child with a disability. However, it is clear from the research to date that the relationship between the provision of family-centered services and the achievement of positive outcomes for children and their parents is complex and is yet to be fully understood. The present article reviews the research in this area and discusses the links between help-giving practices and child and family outcomes for families who have a member with a disability. The review summarises the extant research in an accessible format and identifies areas for future research.

Keywords: family-centered practice, disability, child and parent outcomes, help-giving practices

## A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability

The way in which professionals support children with disabilities and their families has the potential to enhance or to impede child and family outcomes. Currently, family systems theory underpins many models of service delivery that recognize the interrelatedness of family members and the importance of acknowledging the needs of all family members, not just those of the family member with a disability (Brown, Nolan, & Davies, 2001; Carpenter, 1997; Dunst, Trivette, & Johanson, 1994; Fox, Vaughn, Dunlap, & Bucy, 1997; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Murray, 2000; Turnbull, Blue-Banning, Turbiville, & Park, 1999). Integral to family systems theory is the primacy of the parent-professional relationship where decision-making and planning around mutually agreed upon goals are shared between parents and professionals who engage in a relationship defined by mutual respect, trust and honesty (Keen, 2007).

Falling within the family systems milieu, the family-centered philosophy has developed from both the help-giving (e.g. Fisher, Nadler, & Depaulo, 1983) and the empowerment (e.g. Zimmerman, Israel, Schultz, & Checkoway, 1992) literatures. There are four crucial beliefs that drive the implementation of family-centered services. First, the family and not the professional is the constant in the child's life. Second, the family is in the best position to determine the needs and wellbeing of the child. Third, the child is best helped by also helping the family, and this help may extend to an understanding of the family's community and to providing information that the family needs. Finally, family choice and decision-making in the provision of services, showing respect and affirming families' strengths, enhancing family control

over the services they receive, and emphasising partnerships and collaborations with families are emphasised (Dunst, 2002; Duwa, Wells, & Lalinde, 1993). Family-centered philosophy has been advocated across a wide range of professions from health care (Institute for Family-Centered Care, 2007; Svavarsdottir, 2006), therapy services (Esdaile & Olson, 2004), early intervention (Australian Early Intervention Association, 1998), early childhood education (Keyser, 2007), special education (Murray & Mandell, 2006), and regular education (Stormshak, Dishion, Light, & Yasui, 2005). While the conceptual literature around family-centeredness supports this wide scale adoption, the evidence base is more limited and further research focused on the processes and outcomes of family-centered practice is needed. Processes relate to the kinds of supports and resources, experiences and opportunities offered while outcomes refer to capacity building effects that may include parent well-being and family quality of life (Dunst, 2005).

The family-centered field can best be described as being in an adolescent phase of development. The discipline has had an important influence on service philosophy and orientation (particularly for young children with a disability) and it has provided research support for several of the crucial hypotheses that underpin family-centered practice. For example, the research has consistently shown that a family-centered help-giving style is closely associated with enhanced parent control appraisals (Dempsey & Dunst, 2004; Dunst, Trivette, Boyd, & Brookfield, 1994; Northouse, 1997). However, for the field to reach its full potential there needs to be an on-going testing of family-centered practice and the important outcomes believed to derive from that practice.

This paper reviews the family-centered empirical literature as it relates to families with a child with a disability and the review is guided by several imperatives. First, there is a need to promote evidence-based practice in family-centered services to enhance the integrity of the profession. Second, there is a need to provide family-centered practitioners with information that will be immediately useful and replicable in their workplaces and a synthesis of the research in this area will assist in achieving this aim. Finally, there is a need for the testing of a coherent model to explain how and why what family-centered practitioners do impacts on families and their children. Without the empirical confirmation of conceptual models a discipline cannot advance beyond its theoretical base.

A potentially useful approach to take in achieving a thorough testing of the assumptions underlying the family-centered philosophy is to develop a framework to facilitate that testing process. Implicit in this approach should be recognition of the relationship between conceptualisation, operationalisation and measurement in understanding the process and outcome variables associated with family-centered services (Babbie, 2007; Hall, 1996). At a basic level, this means examining the relationship between what is done and what results from that action. For example, the encouragement by staff of parents for gains in their child's development (a process) may logically lead to an enhancement of parents' positive beliefs in their parenting skills (an outcome). Such an analysis can be most helpful to practitioners who are striving to improve the outcomes that derive from their interventions, the analysis can be most helpful to researchers with an interest in determining the relationship between key variables that underpin family-centered practice, and the analysis can be most

useful to policy-makers by clarifying the robustness of the conceptual basis of family-centered practice.

### Method

A literature search on family-centered practice and families with a child with a disability was conducted to identify empirical studies that examined the relationship between process and outcome variables. The PsycINFO and ERIC databases were used in this search to identify studies conducted since 1987. Dissertations and conceptual papers were excluded, along with studies with a family-centered nomenclature but lacking in conceptual or practical evidence that the reported study made use of family-centered principles. Several studies using family-centered as a key word did not make use of family-centered principles.(i.e. the studies provided no evidence that support staff followed the defining principles of the family-centered approach described earlier in this paper). A set of 35 studies that met these criteria were included in the review and these studies are listed in Table 1, along with the variables they examined, which have been categorised as either independent, moderating or dependent variables. This approach was favoured over categorising the variables as service delivery processes or outcomes due to the variability found across the studies in the way these variables were treated and the moderating role of some variables. Several studies reported on a single variable only and as this variable has been used as an independent variable in other research it is classified as such here.

**<Table 1 about here>**

### Service Delivery Processes

The manner in which services are provided by professionals to families is crucial to the family-centered approach and the research literature has typically considered

service delivery as an independent variable, reflecting its role as a process in the achievement of desirable outcomes for children and families. An important consideration in an examination of family-centered practice is to establish objective procedures to determine the extent to which services are family-centered. Three approaches are evident in the literature. First, some instruments have been developed to permit staff to complete self-evaluations of their service (e.g. McWilliam & Winton, 1990; Murphy, Lee, Turnbull, & Turnbull, 1995). Second, there is one report of independent raters' assessments of videotaped exchanges between staff and parents (Goetz, Gavin, & Lane, 2000), and one case study approach to understanding the interaction between parents and professionals (Dunst, Trivette, Gordon, & Starnes, 1993). Finally, a much wider range of parent reports of service received have been developed.

Many studies have reported significant differences between parent and staff ratings of the family-centered nature of early intervention services (Dempsey and Carruthers, 1997; Filer & Mahoney, 1996; McWilliam et al., 2000; McBride et al. (1993). These findings suggest that so long as family-centeredness is defined in relation to the specific needs of parents, then professionals' views of the extent to which they are meeting those needs may be unreliable. Since the vast majority of measures of family-centered practice rely on parent scales they, and not professional evaluations, will be discussed here.

In addition, the research reports considerable variation in parents' perceptions of family-centered practice across services (Dunst, Boyd, Trivette, & Hamby, 2002; Mahoney & Bella, 1998; Petr & Allen, 1997; Trivette, Dunst, & Hamby, 1996b;



VanRiper, 1999). Consequently, a family-centered mission statement does not guarantee that parents will perceive the service to be family-centered. This finding lends support to the use of parent report instruments despite their subjective nature and to use multiple data sources to better understand parental perceptions of help-giving practices (Rodger, Keen, Braithwaite, & Cook, 2007).

Using the Enabling Practices Scale (EPS) (Dempsey, 1995), Dempsey and Dunst (2004) and Dempsey, Foreman, Sharma, Khanna, and Arora (2001) found significant positive correlations between parents' perceptions of family-centered practice and their reported level of empowerment after the variance related to a range of other variables had been accounted for. These studies included groups of families with a young child with a disability receiving support services in Australia, the United States and India. In a further study, seven internally consistent items from the EPS that measure partnerships between parents and professionals accounted for a substantial amount of variance in both parents' perception of their ability to obtain supports and resources and the degree to which parents perceived they had choice in which staff worked with them (Dunst & Dempsey, 2007).

Dunst, Trivette and Hamby (1996) used the Helpgiving Practices Scale (HPS), to show that family-centered service provision was significantly related to the extent to which parents perceived they were able to obtain needed resources, supports and services from the target service. The HPS has been used extensively in family-centered research (see Table 1).

Several studies have made an important contribution to understanding the components of help-giving practices and how those components are differentially associated with service outcomes. For example, the EPS comprises three factors measuring the level of comfort, participation and autonomy by parents in their relationship with professionals (Dempsey, 1995). Dempsey and Dunst (2004) found that the comfort and autonomy factors from the EPS accounted for the majority of, and for approximately equal amounts of, increases in empowerment in families in the United States and in Australia. Using the HPS, Dunst (1997) and Dunst et al (2002) demonstrated that while parents' perceptions of how comfortable they felt in their relationship with staff remained stable across services with different levels of family-centeredness; higher levels of parent participation were always found in family-centered services.

Similar findings in parents' perceptions of help-giving across services were found by King, Rosenbaum and King (1997), Judge (1996) and Granat, Lagander, and Börjesson (2002). More recently, King and her colleagues (2003) found that while both parents and staff strongly believed in the principles of family-centered practice, staff were less likely than parents to note the difficulties of implementing the approach. In addition, parents' perception of the family-centered support they received was significantly associated with satisfaction with the service, with reduced stress and with higher emotional wellbeing (King, King, Rosenbaum, & Goffin, 1999).

Several studies have shown a low correlation between frequency of contact between parents and helpgivers and measures of parental control, and no association between

frequency of contact and help-giving practices (Dempsey et al., 2001; Trivette, Dunst, Boyd, & Hamby, 1995). Taken together, these results are consistent with Dunst, Trivette and Hamby's (2007) meta analysis of family-centered helpgiving practices research which found that help-giving practices are related to a variety of child and family outcomes consistent with the assumptions of family-centered practice described earlier in this paper.

### Parent and Child Outcomes

Researchers in the area of family-centered planning have been interested in determining what outcomes are achieved for children and their parents who participate in services that ascribe to a family-centered approach. To this end, dependent variables identified in the selected studies include parenting stress, competence and locus of control and aspects of child development and behaviour. Some child and parent characteristics may, however, be more appropriately identified as moderating variables but there is a need for further research to clarify the nature of these relationships.

#### *Parent Stress and Well-Being*

The association between parent stress and family-centered support has been examined by several studies. Mahoney and Bella (1998) found no significant relationship between the nature of the service that parents said they received and perceived stress. In contrast, O'Neil, Palisano and Westcott (2001) and van Schie (2004) found that help-giving practices explained a moderate amount of variance in parent stress. A recent study by Keen, Rodger, Couzens, & Muspratt (2008) found child-related parenting stress improved for families who received a family-centered intervention but no similar gains were found for parents in a matched control group.

There is conflicting evidence whether stress may be best considered as an outcome and not an intervening variable in the family-centered model. King and her colleagues (1999) found that help-giving practices, while having a small but significant and direct relationship with stress, demonstrated a stronger association with stress via parents' satisfaction with services. While satisfaction with services was not measured by Thompson et al. (1997), parent stress played an important moderating role in the relationship between family-centered practice and empowerment. Finally, VanRiper (1999) reported a small but significant association between parents' psychological well-being and help-giving practices.

#### *Measures of Control*

The family-centered literature has also used a variety of measures to assess parents' perceived empowerment and control over their life circumstances. The Family Empowerment Scale (FES) measures a family's perception of their empowerment across two dimensions: level (e.g. interactions with individuals, with service staff and with community organisations) and expression (e.g. a belief in the ability to bring about change, participation in advocacy activities) of empowerment (Koren, DeChillo, & Friesen, 1992). The FES has been shown to be closely associated with the family-centeredness of services in several studies. For example, Dempsey et al. (2001) and Dempsey and Dunst (2004) found that help-giving practices accounted for the largest amount of variance in empowerment and that no other variable used in the studies was significantly associated with empowerment for four of five samples of parents. Further, Thompson et al. (1997) demonstrated that family-centered support and parent stress have a positive and a negative relationship with parent empowerment, respectively.

Dunst et al. (1994), Dunst, Trivette, and Hamby (1996), Trivette et al. (1995), Trivette, Dunst and Hamby (1996b) and Judge (1996) found that the extent to which families reported they were able to obtain needed resources and services was significantly related to help-giving practices. Finally, Dunst, Trivette and LaPointe (1994), Trivette, Dunst, Hamby, and LaPointe, (1996) and Judge (1997) found a strong and significant relationship between parent empowerment and help-giving practices.

### *Parenting Competence*

Although it is a strong feature of family-centered philosophy (Dunst et al., 1988), there is limited evidence of a significant association between the use of help-giving practices and the development of parenting competence. Heller, Miller and Hsieh (1999) found increased caregiving self-efficacy for parents with an adult child with intellectual disability versus a control group following a family-centered intervention. In addition, a family-centered intervention with families with a child with autism led to improvements in parenting competence in an experimental group, but not for a control group of parents (Keen et al., 2008).

### *Child Development*

The relationship between family-centered practice and child development has also received little attention in the family-centered research. Mahoney and Bella (1998) found no significant relationship between these variables. However, in a study of over 500 parents, Dunst (1999) showed that the only significant predictor of child progress

in a multivariable model was the extent and nature of parenting supports provided by early intervention workers.

#### *Child Behavior Problems and Level of Disability*

As might be expected, child behavior problems have been shown to be significantly associated with a number of measures of parental emotional wellbeing (King et al., 1999). However, this study did not clarify whether parental depression may contribute to behavior problems. The severity of the child's disability does not appear to be significantly associated with the provision of help-giving or to parent empowerment (Dunst, 1999). A small but significant correlation between child age, but not child disability, and help-giving practices was reported by Judge (1997).

#### Moderating Variables

Family-centered theory acknowledges the importance of a range of variables in moderating the impact of family-centered practice on desirable child and parent outcomes. These moderating variables have been variously presented as both dependent and independent variables in the selected studies and they have included characteristics of the study participants, parents' satisfaction with support, and parent control attributions.

#### *Characteristics of Children, Families and Staff*

The research findings are generally consistent in showing little relationship between a variety of demographic characteristics of parents, children and staff and process and outcome variables in family-centered services. For example, Dempsey and Dunst (2004) and Dempsey et al. (2001) found no significant correlation between parents' educational training, employment status and the age of their child and parents' sense of control. DeChillo, Koren and Schultze (1994), using a wider range of demographic

variables, found no significant differences in reported levels of collaboration with staff across demographic categories. Parent educational qualifications, parent age, parent membership of support groups and the presence of child behavior problems accounted for very little of the variance in parent beliefs about family-centered practices in a study by King and her colleagues (2003). The same study found that receiving training in family-centered practice and professional experience explained a small but significant amount of the variance in staff beliefs about family-centered practice. These results are also consistent with research findings by Judge (1996).

Parent demographic variables (education, employment and income) had a significant inverse relationship with child behavior problems in a study of over 170 parents of young children with a disability (King et al., 1999). In this study, while the level of the child's disability was an important predictor of the financial and personal impact of care, it did not make important contributions to parent stress, wellbeing and satisfaction with the service provided to the family. Trivette, Dunst and Hamby (1996a) found that higher income families were less likely to report help-giving practices as empowering as lower income families. Finally, families involved with an advocacy organisation for the inclusion of school students with a disability reported lower levels of help-giving practices and higher levels of empowerment than families not involved with advocacy services (Dempsey et al., 2001).

Staff characteristics have not been well examined. Two studies have reported differences in parents' perceptions of collaboration with staff and parent control across staff professional disciplines (DeChillo et al., 1994; Trivette, Dunst, & Hamby, 1996b). McWilliam and colleagues (2000) found that while type of agency (e.g., early

intervention program, health department) was the strongest predictor of perceived family-centeredness, setting (e.g., home, clinic) and staff experience were also predictors

#### *Satisfaction with Support*

Many studies show a significant correlation between help-giving practices and parent satisfaction with the service they receive (DeChillo et al., 1994; Dempsey et al., 2001; Dempsey & Dunst, 2004; McBride et al., 1993; VanRiper, 1999; van Schie et al., 2004). In addition, Law and colleagues (2003) demonstrated that the strongest predictors of parent satisfaction were the extent of a family-centered culture within the relevant organisation and parents' perceptions of the extent to which service practices were family-centered. Parents display a higher degree of satisfaction when family-centered service is provided and lower satisfaction when it is not provided (Romer & Umbreit, 1998).

#### *Parent Control Attributions*

Judge (1996) reported strong associations between both personal control and control over the nature of early intervention services, and help-giving practices. Frequency of contact between parents and professionals was also closely associated with these control measures in this study.

Locus of control had a moderate but non-significant relationship with parent empowerment in a study by Dempsey and Dunst (2004). Dempsey et al. (2001) found a significant relationship between locus of control and empowerment in one of two groups of parents. In one of these groups (parents who were members of an advocacy organisation), those with more internalised locus of control tended to report higher



levels of empowerment. In both of these studies, help-giving practices had a small and non-significant relationship with locus of control.

The extent of collaboration between parents and professionals was strongly related to parents' perceived self-efficacy in a study of over 200 parents of children receiving mental health services (Reich, Bickman, & Heflinger, 2004). Furthermore, this relationship was demonstrated by parents at baseline, at three months and at 12 months after a parent training program.

#### Discussion and Future Research Needs

A review of the family-centered literature reveals a relatively small research base on which to understand the relationships that exist between service delivery processes and child and parent outcomes. The model presented in Figure 1 reflects our current knowledge of these relationships based on the research literature. Briefly, family-centered help-giving is directly related to locus of control, self-efficacy and satisfaction with the support parents receive, and indirectly related to a number of parent and child outcomes. Further, the model shows that parent appraisals are directly related to parent and child outcomes and that the former mediate the impact of help-giving on parent and child outcomes.

#### <Figure 1 about here>

Several of the relationships shown in Figure 1 are strongly supported by the family-centered research literature. There is consistent support of a strong relationship between help-giving practices and parents' reported empowerment and control over important aspects of their lives. This relationship holds true for families from many cultural backgrounds and for families with a wide variety of demographic characteristics. Further, the literature has also consistently demonstrated that help-

giving by service providers which incorporates a participatory component is most strongly associated with a range of desirable family outcomes. That is, for outcomes to be optimised, help-giving needs to do much more than foster a respectful and empathetic relationship between professionals and parents. Finally, many studies consistently show that the use of help-giving practices are closely related to parent satisfaction with the professional support they receive.

Although the evidence is not as strong, several studies support an association between help-giving practices and both a number of parent control appraisals and parent stress and wellbeing. There is very little research support to confirm the assumed links between help-giving practices and both child development and parenting competence. Bailey et al (2006) note that there has been a lack of agreement and a consequent lack of consistency in the conceptualisation of family outcomes in research on families for young children with a disability. Their identification of five family outcomes, developing from stakeholder research, is an example of a socially valid process that may assist in the development of future research frameworks.

That there are some important variations in the level of confidence we have about several assumptions inherent to the family-centered philosophy is not surprising, given the relatively limited research literature in this area. However, because the philosophy has been widely adopted as 'best practice' in a variety of disciplines, it is crucial that important gaps in the research backing for family-centered support are addressed. First, it is crucial that the field undertakes further longitudinal studies to permit some confident assertions about the causal relationship between relevant variables that the current family-centered research, which is dominated by cross-

sectional studies, does not allow. For example, at the moment it is not possible to provide consistent evidence that a range of child and family outcomes improve over time as a consequence of help-giving practices. A second crucial need is for future research to determine the extent to which help-giving practices are related to both parenting capabilities and child outcomes such as child development and reduction of child behavior problems. In this regard, both experimental research and research that incorporates a wider range of relevant variables will assist.

In conclusion, the family-centered philosophy continues to hold much promise in the generation of desirable outcomes for children with a disability and their families. The existing limited research base has done much to confirm several of the important features of this philosophy. However, for the family-centered philosophy to achieve its full potential and to ensure that it becomes more than just an interesting feature of family-professional partnership theory, future family-centered research needs to systematically target a number of important areas in need of clarification.

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